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Torque

Magazine

ISSUE 2
2006

**WIN A
HOLIDAY!**

Bumper 24 page issue

**Koncert for Northcott
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Start pressure area care before it becomes a problem

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 **SANICARE**
Australia & New Zealand

Telephone directory

Northcott Spina Bifida Group

1 Fennell Street, North Parramatta 2151
Tel: (02) 9890 0990
sbgroup@northcott.com.au

Northcott Disability Services

1 Fennell Street, North Parramatta 2151
Tel: (02) 9890 0100

The Sydney Children's Hospital

High Street, Randwick 2031
Tel: (02) 9382 1111
Spina Bifida Clinic Tel: (02) 9382 1595

Prince of Wales Hospital - Randwick

Adult Spina Bifida Clinic
4th Wednesday of every month with
Dr Engel. Make appointments through
"Adult Outpatients" on (02) 9382 0400

Westmead Hospital (Adults)

Sister June Kelly
Wednesdays:
Tel: (02) 9845 5555 page 12545
Other Days: leave a message with Ward
A4C or if more urgent please phone
Medical Rehabilitation on (02) 9845 7800

The Children's Hospital at Westmead

Cnr Hawkesbury Road and Hainsworth
Street, Westmead 2145
Sister Julie Dicker
Tel: (02) 9845 2802

Spina Bifida Unit Secretary - Westmead

Pamela Larbalestier
Tuesday to Friday, 8am - 4pm
Call Pamela to make appointments for
the Spina Bifida Clinic which occurs every
Friday on (02) 9845 2769

John Hunter Children's Hospital

Lookout Road
New Lambton Heights
Spina Bifida Clinic
Contact: Clinic Co-ordinator Dr John Stuart
on (02) 4921 3750

Central Coast Spina Bifida Nurse

Mrs Mikey Oxby - Wyong Hospital
Tel: (02) 4394 8275 or 0413 482 528

JOBMATCH

(An employment service for people with
disabilities)
1 Fennell Street North Parramatta 2151
Tel: (02) 9890 0970

SUPPORT GROUPS:

If you would like to attend one of the Spina
Bifida Parent Support Groups in your area
please contact one of the following:

Wollongong Area

Jessie Norwell
Tel: (02) 4256 6484

Canberra Area

Jan Pummeroy (02) 6298 8394
Eileen Catanzariti (02) 6241 6713

Central Coast

Ann and Philip Hudson (02) 4341 7972

Newcastle Support Group

Patsy Osbourne (02) 4987 2780
Joan Gatt (02) 4948 6096
Therese Barlow (02) 4987 2161

Hydrocephalus Support Association

Jun Steinfurth (02) 9586 1057

National Continence Helpline

Freecall: 1800 330 066
Monday to Friday, 8am - 8pm

Paraquad - Tel: (02) 8741 5600

Sanicare - Tel: (02) 9437 9611



northcott
spina bifida group

NORTHCOTT SPINA BIFIDA GROUP ORDER FORM FOR PADS & NAPPIES

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Please return your order with a cheque or money order **(NO CASH PLEASE)** to:
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PO Box 4055 PARRAMATTA NSW 2124

Name: _____ Phone: _____

Delivery Address: _____

Post Code: _____

Amount Enclosed: \$ _____

- Please indicate in the box how many of each product you would like.
- Please note the delivery fees.
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Independence Solutions Products - A home-direct delivery service of ParaQuad

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| <input type="checkbox"/> Tena Lady Mini Ultra Thin \$36.60 (10 pkts x 20) 15120001 | <input type="checkbox"/> Tena Slip Super Small \$18.95 (1pkt x 25) 15120171 | <input type="checkbox"/> Abriform Medium Plus \$19.55 (1pkt x 26) 15000015 |
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| <input type="checkbox"/> Tena Lady Super \$21.95 (6 pkt x 8) 15120030 | <input type="checkbox"/> Huggies Dry Nights, 15120181 Size L 30 - 40kg \$49.95 (6 pkt x 14) | <input type="checkbox"/> Abriform Small Super \$17.25 (1pkt x 28) 15000005 |
| <input type="checkbox"/> Depend Shields \$3.60 (1 pkt x 10) 15230020 | <input type="checkbox"/> Depend Normal Brief Large \$45.10 (3 pkt x 20) 15230125 | <input type="checkbox"/> Tena Flex Super Medium \$26.15 (1 pkt x 28) 15120470 |
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Hello and welcome to this bumper edition of the new look Torque Magazine! Highlights include promotion of Spina Bifida Awareness Week (SBAW) 2006 and the Ageing with Spina Bifida Forum. As always, we also have some great stories about the lives and achievements of people with spina bifida. Torque encourages letters from clients, family members and carers sharing your story for a chance to win a holiday! We are particularly keen to get a range of stories from people from a variety of cultural backgrounds. Concert for Northcott CDs are also available as prizes to the first five people who provide interesting and creative ideas for SBAW 2007. Let us know what you think!

You will note on page four that the Spina Bifida Group of NSW recently changed its name to the Northcott Spina Bifida Group. The services won't change, just the name. Speaking of change, I also want to introduce Jenny Smith, who is the new Administration Support for the Group. Jenny is doing a great job filling in for Kayleen while she is on maternity leave, having just given birth to a lovely baby girl called Emily. Wishing you and your family a great Christmas and New Year!

Enjoy!

Anita Fisher



Cover photo: Kimberley White meets Spinasaurus.

Spinasaurus spreads the word – Page 12

THE PUBLISHERS OF THIS MAGAZINE HAVE MADE EVERY EFFORT TO ENSURE THE ACCURACY OF INFORMATION, BUT NO RESPONSIBILITY WILL BE TAKEN FOR ERRORS OR OMISSIONS. NO ENDORSEMENT OF ANY PRODUCTS OR PROCEDURES WHICH APPEAR IN THE PUBLICATION ARE GIVEN OR IMPLIED BY THE NORTHCOTT SPINA BIFIDA GROUP. THE OPINIONS EXPRESSED BY WRITERS ARE NOT NECESSARILY THE VIEWS OF THE NORTHCOTT SPINA BIFIDA GROUP. TO SUBMIT ARTICLES, LETTERS OR PHOTOGRAPHS, WRITE TO: TORQUE MAGAZINE, PO BOX 4055, PARRAMATTA NSW 2124.

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A division of Northcott Disability Services
(Established in 1929 as The NSW Society
for Crippled Children)

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New name, same group

THE Spina Bifida Group of NSW has undergone a name change and will now be known as the Northcott Spina Bifida Group. The name change was decided after a number of services and entities that operated as divisions of Northcott took on the Northcott name to gain greater recognition.

The Spina Bifida Group of NSW was first formed in 1969 by a group of parents who were having difficulty finding support and information for people with spina bifida. In 1985, Northcott assumed responsibility for the provision of services to members. The group has grown to include more than 270 financial members, including individuals with spina bifida, their family members and professional associates.

The Northcott Spina Bifida Group will continue to provide services across NSW and operate from

Northcott's central office in North Parramatta. Anita Fisher, Manager of the Northcott Spina Bifida Group, stressed that the name change will not alter any of the services that the Group provides.

"We will continue to provide services relevant to people with spina bifida and their families across NSW," Ms Fisher said.



To find out more, please contact the Northcott Spina Bifida Group on (02) 9890 0990.

Introducing Jenny

MY name is Jenny Smith and I am working in the position of Administration Support for the Northcott Spina Bifida Group, filling in for Kayleen while she is on maternity leave for approximately eight months. I feel privileged to be working with a great team of caring people.

My previous work experience was Administration Support with an aged care organisation where I worked closely with elderly clients and their families for many years.

I am the mother of seven boys and grandmother of five - two girls and three boys. In my spare time, I enjoy listening to music, quilting (though I'm not sure if only three squares completed in 12 months counts

as a hobby), scrapbooking and gardening.

I look forward to being able to speak with you during my time here and to offer assistance wherever possible.

My office hours are 9.00am to 2.30pm Monday to Friday, but if you need to ring outside these hours, please leave

a message and I will call you back. My phone number is (02) 9890 0990 or you can email me on sbgroup@northcott.com.au.



Jenny

**WIN
A HOLIDAY!**

AS always, we are keen to get your feedback about *Torque*. We encourage you to comment on the articles and stories that appear in the current edition. The person who submits the best letter to the editor will have a chance to win a week away at our Budgewoi cabin! (See advertisement below)

Need a holiday...



THE Northcott Spina Bifida Group owns a wheelchair accessible holiday cabin at Budgewoi, on the NSW Central Coast, located on the foreshores of Lake Munmorah.

The cabin has been specifically designed and constructed for use by people with physical disabilities. The cabin can sleep five people, has modern amenities, laundry facilities and a barbecue. A Northcott Freewheeler is also available for use.

For bookings, call the Northcott Spina Bifida Group on (02) 9890 0990, fax (02) 9683 2827 or email sbgroup@northcott.com.au

In the Library

with Judi Lipp

ALLOW us to present two new items in our children's literature collection. *Another Way to Go* is the title of both children's books but the cover illustration shows that one book is for girls and the other for boys. The topic is toileting, the author is nurse, Marlene Lutkenhoff, and the illustrator is Teresa Rodgerson. Marlene edited *Spinabilities and Children with Spina Bifida: A Parent's Guide*.

As our two little characters, Becky and Timmy enjoy their first day at kindergarten, they become concerned that they use catheters and other children do not. Before bedtime, the children discuss this difference with their mother and are reminded of the story of their births. The opening in their backs required surgery and nerve damage means that catheterisation is just another way to go. Soon Becky and Timmy will be able to do this for themselves.

The book publisher and supplier is the Spina Bifida Association in the United States – www.sbaa.org
In addition, for our adult readers:

The Ultimate guide to sex and disability: for all of us who live with disabilities, chronic pain & illness is written by Miriam Kaufman, Cory Silverberg and Fran Odette and published in 2003 by Cleis Press. This book introduces 14 myths about disability and sexuality with the intent to deactivate these myths. A broad range of sexual issues are covered and there is also information about available resources. Illustrator Fiona Smyth provides graphic drawings that enhance the work.

Judi Lipp

Librarian

Ph: (02) 9890 0161

judil@northcott.com.au



www.linkonline.com.au

CHECK out the above website for a fantastic online magazine with interesting articles on relevant issues as well as achievements of people with a disability. The magazine pays readers for their comments and there is also a great photo competition.

Cervical screening for women with disabilities

THERE are many barriers that affect the ability of women who have a disability to access cervical screening. Lack of knowledge about when and where to have a Pap test, embarrassment, anxiety, male GP, past negative experiences and past history of sexual assault are some reasons why women do not access cervical screening. Additional barriers experienced by women with disabilities may be stereotyping and negative attitudes from health professionals, physical access, communication difficulties, limited financial resources and physical limitations.

The NSW Cervical Screening Program, in conjunction with the Centre for Developmental Disability Services (CDDS), has developed guidelines for health professionals to improve access and outcomes for women with disabilities. These guidelines include communication strategies, consent arrangements, improving physical access and practical tips for performing Pap tests for women with disabilities. There are also guidelines for breast screening, menstruation, sexual health, pregnancy choice and menopause.

The guidelines are available on the website: www.csp.nsw.gov.au or in hard copy from NSW Cervical Screening Program, Locked Bag 7118, Parramatta BC 2150.

Original reference: NSW Cervical Screening Program and Centre for Developmental Disability Studies Preventative Women's Health Care for Women with Disabilities.

Reproduced with permission from: FPA Health Newsletter

Need some C.L.U.E.S.?

THE C.L.U.E.S. (Community Living Useful Elements for Survival) course is a life skills course that is run each year as part of the Merrylands Independent Living program. The course is designed to assist young adults with a disability who are taking steps to greater independence. Topics include: Safety in the Community, Health, Nutrition and Body Care, Relationships, Self Esteem, Stress Management, Communication, Living Alone or Sharing, and Budgeting.

Feedback from this year's course includes:

- "I really enjoyed it"
- "I found the whole course really helpful and useful"
- "The presenters were great"
- "I learnt a lot - informative"



The dates and venues for next year's course are yet to be confirmed. Please contact Jenny Sanders on (02) 9890 0902 for more information and to put your name on the mailing list for C.L.U.E.S 2007!

Spina Bifida Clinic visits Tamworth

Supported...Northcott client Bradley Moylan (left) with Dr Carolyn West and Northcott client Tara Dixon.



IN October 2006, specialists from The Children's Hospital at Westmead visited children and adults at a special spina bifida clinic at Northcott Disability Services Tamworth regional office.

Specialist nurse Julie Dicker and Dr Carolyn West, Staff Specialist at the Spina Bifida Rehabilitation Unit at The Children's Hospital at Westmead, assessed about 14 people from surrounding areas during the two days of the clinic.

Funded by Northcott and organised by The Children's Hospital at Westmead, the spina bifida clinic is a regular service offered in regional areas of NSW. Northcott staff in Tamworth also received spina bifida training from the visiting team enabling them

to provide further service to people with disabilities in the area.

April Cochrane, Northcott Disability Services Regional Team Leader, said the travelling clinic eased the time, expense and inconvenience placed on families and individuals who often have to travel to metropolitan areas to be assessed by a specialist.

"I'm delighted that the clinic visits Tamworth, as most of our clients would normally have to travel to Sydney to receive a routine follow up. This takes the pressure off families and people with disabilities," Mrs Cochrane said. "It is fantastic that Northcott staff receive an opportunity to be trained by such specialists."

Independence Solutions clinic

INDEPENDENCE Solutions, specialists in continence issues and products, wound care and other related issues, now offers a free clinic service to its customers.

The team at Independence Solutions will help you find the right product and the correct way to use it. A Clinical Nurse Consultant will work with you at no charge to focus on already identified health issues and equipment for continence and wound care.

When: Every Wednesday between 9:30am and 4:00pm
Where: 6 Holker Street, Newington NSW 2127

To make an appointment contact Clinical Nurse Consultant, Kylie Wicks on 0418 614 765. An assessment form will be completed and a clinic time and date booked.

Price change - nappy and pad orders!

YOU may notice that there are some recent changes to the prices for nappy and pad orders through Independence Solutions (Paraquad) on page 22. For more information, contact Jenny Smith from the Northcott Spina Bifida Group on (02) 9890 0990.

Bladder transplant

A new medical breakthrough pioneered at Wake Forest University in North Carolina has allowed people who had poor bladder function because of spina bifida to receive a fully functioning laboratory-grown bladder. The results from the study were released in April 2006 and Kaitlyne McNamara is the first person to receive the bladder transplant. *Torque* editor Tereza Culina caught up with her.



Kaitlyne McNamara (second on left) with her family

Kaitlyne McNamara of Middletown in America is an outgoing, active and unique student. The 17-year-old, who has spina bifida, is the recipient of one of the world's first re-engineered bladders.

The bladder transplant was also performed on seven other patients aged four to 19 who had spina bifida and problems with urinary control because of their disability. The transplant involved doctors extracting muscle and bladder cells from a small piece of the patient's own bladder. The cells are then layered on a mould shaped like a bladder. In a few weeks, the cells produce a new bladder, which is then implanted into the patient. With the engineered bladders grown from the patient's own cells, there is no risk of rejection.

For the children and teenagers involved in the study, the lab-grown bladders reduced leaking from their bladders. For Kaitlyne McNamara, the medical advancement has made her life a little more normal. After undertaking the surgery in February 2001, Kaitlyne McNamara was able to confidently attend her prom and now enjoys attending social events.

"The surgery has meant that I don't have to wear

diapers and change my clothes all of the time and I can go out with my friends to a movie or dinner without having to worry when I stand up if I'll be wet or not," Kaitlyne said. "I also got to wear a real pretty prom dress to my Junior prom that I wouldn't have been able to wear with diapers."

Kaitlyne's mother Tracy is delighted that the medical advancement has been able to transform her outlook on life.

"The surgery changed the quality of her life in a way that we had never dreamed," Mrs McNamara said. "It made her so much more confident."

"I think the procedure offers many advantages to people with spina bifida and other disabilities as well," Mrs McNamara said. "We are talking about the ability to grow organs in a lab – organs grown by the persons' own cells, so there are no rejection issues, no transplant lists and no waiting for donors."

Dr Anthony Atala and his colleagues from Wake Forest University in North Carolina are positive that the study will generate hope in all areas of human organ research, but feel that further study is needed before the approach could be adopted.

Good News!

As mentioned in the last edition of *Torque*, a decision was to be made by Food Standards Australia New Zealand (FSANZ) in October 2006 to determine the mandatory fortification of bread with folate (folic acid) in an effort to reduce the incidence of neural tube defects (NTDs), including spina bifida. Northcott joined a number of other interested individuals and organisations in sending letters of support for the mandatory fortification.

Good news! On 24 October the Australia and

New Zealand Food Regulation Ministerial Council unanimously reinforced their commitment to reduce the number of NTDs in Australia and New Zealand as quickly as possible through the mandatory fortification of food with folic acid. The adequate intake of folic acid prior to and during the early stages of pregnancy has been medically proven to reduce the incidence of NTDs.

For more information go to: www.ifglobal.org or www.foodstandards.gov.au

STRONGER TOGETHER -

a new direction for disability services in NSW 2006 - 2016

THE lemma State Government recently announced its new 10 Year Disability Plan entitled STRONGER TOGETHER – a new direction for disability services in NSW 2006 - 2016!

Highlights of the new package for the first five years include:

1. **Strengthening families - enabling children and young people with a disability to grow up in a family and participate in the community**

(\$6 million in 2006/07 and \$83 million over five years)

Highlights

- Continuing increases in intensive, innovative and flexible support packages for children and young people and their families. By the fifth year there will be an additional 1,800 places a year.
- 200 new therapy places for children with a disability in 2006/07. By the fifth year, the number of therapy places will be 960 a year.
- 80 additional flexible respite places for children with a disability in 2006/07. By 2010/11, there will be 450 new respite places for children and young people.

2. **Count me in...promoting community inclusion - supporting adults with a disability to live in and be part of the community**

(\$87 million in 2006/07 and \$1,013 million over five years)

Highlights

- Expansion of community participation programs for people with a disability from three days a week to four days and five days for people with very high support needs commencing in 2007. This will assist 1,990 people next year.
- 180 new places for innovative supported accommodation options in 2006/07. By 2010/11 there will be 990 places.
- 130 places in day programs for adults with a disability in 2006/07 at \$2 million and 780 places over five years.
- 70 intensive in-home support places in 2006/07, with 320 places over five years.
- Introduction of flexible community support packages with 40 packages over five years.
- Up to \$80 million over five years (with the Commonwealth Government contributing half) to prevent young people entering nursing homes, improve the circumstances of young people in nursing homes and develop alternative models of support for young people living in nursing homes.
- 400 new therapy places for adults with a disability in 2006/07. By 2010/11 there will be 1,920 new therapy places for adults.
- 670 additional flexible respite places for adults with a disability in 2006/07. By 2010/11 there will be 810 new respite places.

3. **Improving the system's capacity and accountability - fairer and clearer ways to access services with greater accountability and more opportunities for innovation**

(\$61 million in 2006/07 and \$242 million over five years)

Highlights

- Build research and development capacity.
- Develop specialist accommodation with \$23 million over five years (includes capital) - large residential centres will continue to close over time with some of the properties being redeveloped into contemporary village-style accommodation and support.
- 100 new case managers providing assistance to 4,000 people with a disability and their families per year.
- Expand training for Government and non-government disability workers.

Copies of the summary version and full document entitled Stronger Together – a new direction for disability services in NSW 2006 – 2016 can be obtained by calling DADHC on (02) 8270 2000 or email info@dadhc.nsw.gov.au

Age is no barrier

NOELENE Lanham of Kotara in Newcastle is the oldest person with spina bifida in NSW. The 67-year-old, who lives on her own, enjoys her independence.

Noelene, who uses a walking frame for secure mobility, was diagnosed with spina bifida at birth.

"Doctors said I wouldn't make it past school age and that puberty would kill me," Noelene said. "I've defied the odds."

Having volunteered in her local community and worked full-time up until her retirement a few years ago, Noelene now enjoys spending most of the time with her two daughters, Megan and Leana, and her 12 year old grandson, who she says keeps her occupied most of the time.

Noelene does all her own housework and is proud of her independence.

"I vacuum the house and do all the embroidery on my cushions," Noelene said. "I even made every costume my daughters wore to ballet, as once I realised I couldn't play sports I turned my vocation into sewing."

Noelene has fond memories of her childhood and remembers the time she spent sailing with her father.

"I first sailed with my father when I was twelve and sailed with him right until he retired," Noelene said. "I still have the rope burns to prove it."

A positive spirit, a defiant attitude and the ability to not let your disability hinder your day-to-day life is what Noelene cites as the key to her longevity.

"It's not going to rule me, I'm going to rule it," Noelene said.

Are you older than Noelene? If so, we'd love to hear from you. Please contact Northcott on (02) 9890 0990.

Memories...Noelene Lanham at two years of age



Fighting fit...Noelene Lanham of Kotara

Raising children network website

THE Parenting Research Centre has recently launched a website for parents called the Raising Children Network. The website is written for parents in general but does have some specific information on children with a disability. The Parenting Research Centre would be interested in your thoughts on the site and your feedback regarding how useful the site is to you as a parent. It would also be beneficial if you could please include the age of your child, the disability your child has been diagnosed with, and at what age your child was diagnosed. Please be assured the information you provide will only be used to direct further research to better their provision of information to parents of children with disability.

The website can be found at: <http://raisingchildren.net.au>. For more information contact: Vincent Lagioia, Senior Project Officer, Parenting Research Centre on vlagioia@parentingrc.org.au

Reprinted from IDEAS Inc E-News Issue 25, 2006

Teacher in-training triumphs with scholarship

UNIVERSITY student Jessica Chandler of Armidale is fulfilling her life-long ambition to become a teacher, with the help of a \$2500 scholarship from the SpineCare Foundation, a division of Northcott Disability Services.

In her second year of a Bachelor of Education (Primary) degree at the University of New England, Armidale, the 20-year-old, who has spina bifida and hydrocephalus, was one of seven recipients to be awarded the SpineCare scholarship.

Studying to become a primary teacher, Jessica is enjoying her degree, using the money from the scholarship to pay for textbooks and transport.

The bright student moved to Armidale to live in a flat closer to university. She enjoys her independence and is passionate about achieving her goals. After completing a practical at Moree East Public School, Jessica is convinced she wants to make a difference in Aboriginal communities.

"I've always had a rapport with Aboriginal kids and that's a passion of mine," Jessica said. "I know I can make a difference by being a teacher and want to be someone that people can look up to."

Jessica's father is also a teacher. She says he is her greatest role model and had the most influence on her strong work ethic.

"I grew up in a small town with only a few teachers and seeing how respected my dad was within the community was inspiring, as I've always admired my dad as a parent, but now that I'm studying to become a teacher, I admire him as a professional," Jessica said.

Jessica is proud of her achievements and her future direction.

"Making it to university is something I am proud of," Jessica said. "I have my best mates, I'm happy, successful and I don't have to rely on anyone else. It's a great feeling to be independent."

The SpineCare Foundation scholarship aims to assist students with a physical disability to obtain tertiary education in NSW. Only students who have a physical disability, are Australian citizens and study at either TAFE or university are eligible to apply.

Contact Northcott on (02) 9890 0100 for more information, or visit www.spinecarefoundation.org.au

Making a difference... Jessica Chandler
Photo courtesy of *Armidale Express*



From our readers...

THE following is a short essay written by Madeline Kennedy, the 13-year-old sister of Grace Kennedy. Grace is 11 years old and lives with spina bifida. An article on her swimming achievements appeared in Issue 1 of Torque last year. Grace's older sister won the High School Section of a competition called A Blueprint for the Shoalhaven, which was run by her local council, Shoalhaven City Council. Madeline was required to write a 200 word essay on "How to make the Shoalhaven a better place to live".

How to make the Shoalhaven a better place to live

The city of Shoalhaven, on the South Coast of NSW, is a place of natural beauty; 160 kilometres of varied land ranging from mountain ranges in Kangaroo Valley stretching into the beautiful white sandy beaches in Jervis Bay. The Shoalhaven stretches down the coast from Kangaroo Valley to North Durras and houses 95,281 citizens. With the spectacular bushwalks, lookouts and beaches, no one should miss out on this fantastic scenery. As a family with a child who has a disability, we have encountered difficulties including her in family outings and activities. In order for everyone to enjoy the beauty of the Shoalhaven, the issue of access for the disabled and the elderly is important.

There are currently some good boardwalks and walkways that are accessible for the disabled but there is more that needs to be done. Provision of

disabled car parking, toilet facilities, recreational access for young children with disabilities, removal of steps where possible and handrails are just some of the things that could be improved throughout the Shoalhaven.

It would be good to see children's playgrounds include activities that are designed for children with limited mobility. For example, ground level equipment that children can access without the assistance of adults, swings that are wheelchair compatible and ramps onto the equipment.

To make the Shoalhaven a better place to live for all of us, we need to make some easy adjustments that suit children and adults who have limited mobility. Anyone who lives in this amazing part of Australia shouldn't have to miss out on the beautiful scenery and recreational activities that the Shoalhaven provides.

Madeline



Sisterly support...Madeline left and her sister Grace



All smiles...Former Australian wicketkeeper Ian Healy, Melissa's father Patrick O'Hehir and Northcott client Melissa O'Hehir.

Legendary cricketers lunch for Northcott

NORTHCOTT'S 11th Annual Cricket Legends Lunch on October 27, 2006 was a great success. Cricketing greats and supporters took to Star City Casino's Grand Harbour Ballroom to help raise over \$90,000 – proceeds of which will go towards Northcott's respite services.

Northcott client Melissa O'Hehir 18, and her father Patrick were special guests at the lunch. Melissa, who has spina bifida and uses Northcott's Roselands Respite Service, enjoyed the opportunity to meet the cricket legends face to face.

Cricket legends who attended the lunch included Richie Benaud, John Benaud, Trevor Chappell, Greg Matthews, Wayne Holdsworth, Graham Thorpe,

Wayne Seabrook and Geoff Lawson. VIP guests included media personalities Adam Spencer and Tony Squires, entertainer Kamahl, and poet and author Peter "Fab" Fenton.

A discussion panel with various cricket legends on the upcoming Ashes tour kept the crowd on the edge of their seats. However, the true stars of the day were the Northcott clients.

Ian Healy, former test wicketkeeper and master of ceremonies, was superb in his role, working with Adam Spencer to ensure the crowd of over 400 supported Northcott's centre based respite service, which provides a home away from home for children with disabilities on weekends and school holidays.

Wheelchair accessible self guided walking tours

www.selfguidedwalkingtours.com has just released a new wheelchair accessible tour around the Rocks district in Sydney.

The way the tours work is that the visitor goes to the website, pays \$10 on a secure payment system (Paypal), and is provided with login details to download The Rocks tour. The tour consists of a 21 track audio (mp3), containing storytelling tracks at designated points of interest along the way, as well as directional information tracks. The visitor uploads this onto their ipod or mp3 player, or burns it onto a CD to listen to on their

walkman. They also get a map to follow, and information about how to get there. The stories are all genuine, researched truths and legends around the Rocks area.

If you are interested in finding out more, please contact Heidi Lavis on:

Heidi@selfguidedwalkingtours.com

You can also visit the website at:
www.selfguidedwalkingtours.com

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His history has always remained a mystery



SPINASAURUS is a big, blue and friendly dinosaur, the official mascot of the Northcott Spina Bifida Group, and Robyn Stevens is the woman behind the creation.

Robyn is the mother of a 15-year-old boy with spina bifida. She first created the concept of Spinasaurus after she attended regular meetings with the Northcott fundraising committee and found that there was a lack of education within the community about spina bifida.

"I really wanted to create an inventive way to raise awareness of spina bifida, which is how the concept of Spinasaurus emerged," Robyn said. "I thought a mascot would not only be a fun and great way for children to understand, but also for adults to better understand about spina bifida."

Spinasaurus plays an important role in educating the community about spina bifida during Spina Bifida Awareness Week. The mascot has a gap missing in his backbone to represent spina bifida



The woman behind Spinasaurus...Robyn Stevens with her 15-year-old son Charles

and is often used to explain to the children and young adults he visits.

"The midwife was even afraid to hold Charles when he was born because they thought spina bifida was contagious," Robyn said. "I knew from then on that Spinasaurus had to be the way to better educate the community about spina bifida."

Northcott Disability Services Annual Reports

NORTHCOTT held its Annual General meeting in October of this year. Free copies of the Annual Report, including a copy of Northcott's Corporate DVD are available to Northcott Spina Bifida Group members by contacting Jenny Smith on (02) 9890 0990.

National Carer Counselling Program

THE National Carer Counselling Program is funded by the Australian Government and delivered through the Carers NSW Commonwealth Resource Centre by phoning 1800 242 636.

The focus of services will be on the particular needs of the individual carer in relation to the caring role, with a focus on enhancing the carer's overall resilience. Services include six sessions

of short-term counselling, which are delivered by qualified professional counsellors in your local area and the option for telephone counselling.

Counselling may focus on issues, such as:

- Stress management
- Coping skills
- Grief and loss issues
- Transition issues
- Emotional support
- Health and wellbeing
- Practical problem solving techniques

The program opens opportunities for the carer to experience 'talking over' their issues in a professional supported environment. 'Someone to listen' can be a rare opportunity for carers. Fees for counselling session/s are based on need, not the ability to pay. Phone: 1800 242 636.

Tiffanie confronts her classmates

THE following is a speech Tiffanie Hill gave to her classmates during Spina Bifida Awareness Week 2006. The 11 year old decided to speak to her classmates about living with spina bifida. Her mother, Diana McIntosh, was there on the day. "By the time she got to the end, the teacher, half the class and I (listening through the window) were all in tears," Diana said. "It has been the best thing she has ever done as it has been so liberating for her."

"I'm not actually here at school today because I am feeling really sad about school and some of the things that have happened, but I just wanted to tell you a few things about myself. I was born with a condition called spina bifida. This means that my spinal cord was damaged as I was forming and it affects my legs, bowel and bladder. Mum was told by the doctors that I would probably die before I was even born and if I did survive, that I would be severely mentally handicapped and would never walk. I have to have medication for the rest of my life and require complicated medical procedures four times every day and need to use continence products all the time.

I also want to tell you that I love God with all my heart and know that He loves me and accepts me as He made me. I am a strong person, a caring person, a great friend and very talented in a number of areas, if you took the time to find that out. I'm proud of who I am and proud that God has chosen me to speak for all people with disabilities.

I know that it is not cool to tease and pick on people for their differences and problems, which is why I do not do it to any of you, even though many of you do it to me. I don't throw stones at you. I don't trip you or push you over or threaten to bash you up. I don't kick your bag around, smash your lunch box or throw your belongings into the bush. I don't ignore you, laugh at you, call you names and say nasty things to you. I don't leave you out of the group or run away from you just to follow everyone else's lead and try to look cool. I don't show or tell you that I hate you. Instead, I try to love you all as God loves me.

I hope, for God's sake, that if anyone else comes into this class with a disability or a difference of any kind, that you will see their wonderful qualities and take advantage of the

wonderful friendships you could develop. You may be surprised.

I'd like to thank the lovely people in this class who haven't teased me and have shown me support. I have really appreciated it. Thank you."

Liberated...Tiffanie Hill (front) with her mother Diana McIntosh



Help and win!

PLANNING is now underway for Spina Bifida Awareness Week 2007, to be held from September 1-7. The Northcott Spina Bifida Group wants to continue to highlight the achievements of people living with spina bifida during this week. We want to hear from people with spina bifida who use or have used any of Northcott's services. If you would like to share your personal story in the media, simply contact your Northcott representative by June 30.

We are also looking for interesting and creative ways in which to promote the week. The first five people to either email Tereza Culina on terezac@northcott.com.au or mail their suggestions to Tereza at PO Box 4055, Parramatta NSW 2124 will win a copy of the 2006 Koncert 4 Northcott CD. The CDs are usually priced at \$20 and include tracks from all the artists that performed at this year's fundraising extravaganza.

We need your help to make sure Spina Bifida Awareness Week 2007 is just as successful as Spina Bifida Awareness Week 2006!



Spina Bifida Awareness Week 2006

Spina Bifida Awareness Week 2006 (September 1 to 7) was celebrated with a variety of fun, informative and educational events across NSW.

The Northcott Spina Bifida Group of NSW used the week this year to highlight the achievements of people living with spina bifida and to remind the community about the importance of folate intake before and during pregnancy.

In Sydney, more than 150 people celebrated the start of the week by attending Koncert 4 Northcott at St Patrick's Cathedral in Parramatta. Held for the second consecutive year, Koncert 4 Northcott was organised by Diana McIntosh, whose daughter Tiffanie Hill has spina bifida. Tiffanie played the piano and also performed a dance routine on the day. Performances by The Robertson Brothers, Circular Keys Chorus, singer songwriter Ryan Coughlan, cabaret vocalist Luke Redmond, flute and guitar duo Diana McIntosh and Jason Hill and easy listening vocalist Robert D'Costa kept the audience entertained. A mini Disability and Ageing Daily Living Expo took place at the concert for the first time, with displays from various disability organisations.

The Northcott Spina Bifida Group hosted an Ageing with Spina Bifida Forum to discuss issues people with spina bifida can expect as they age (see page 13)

In Wagga Wagga, Northcott staff, clients and their families attended a barbecue at Wagga

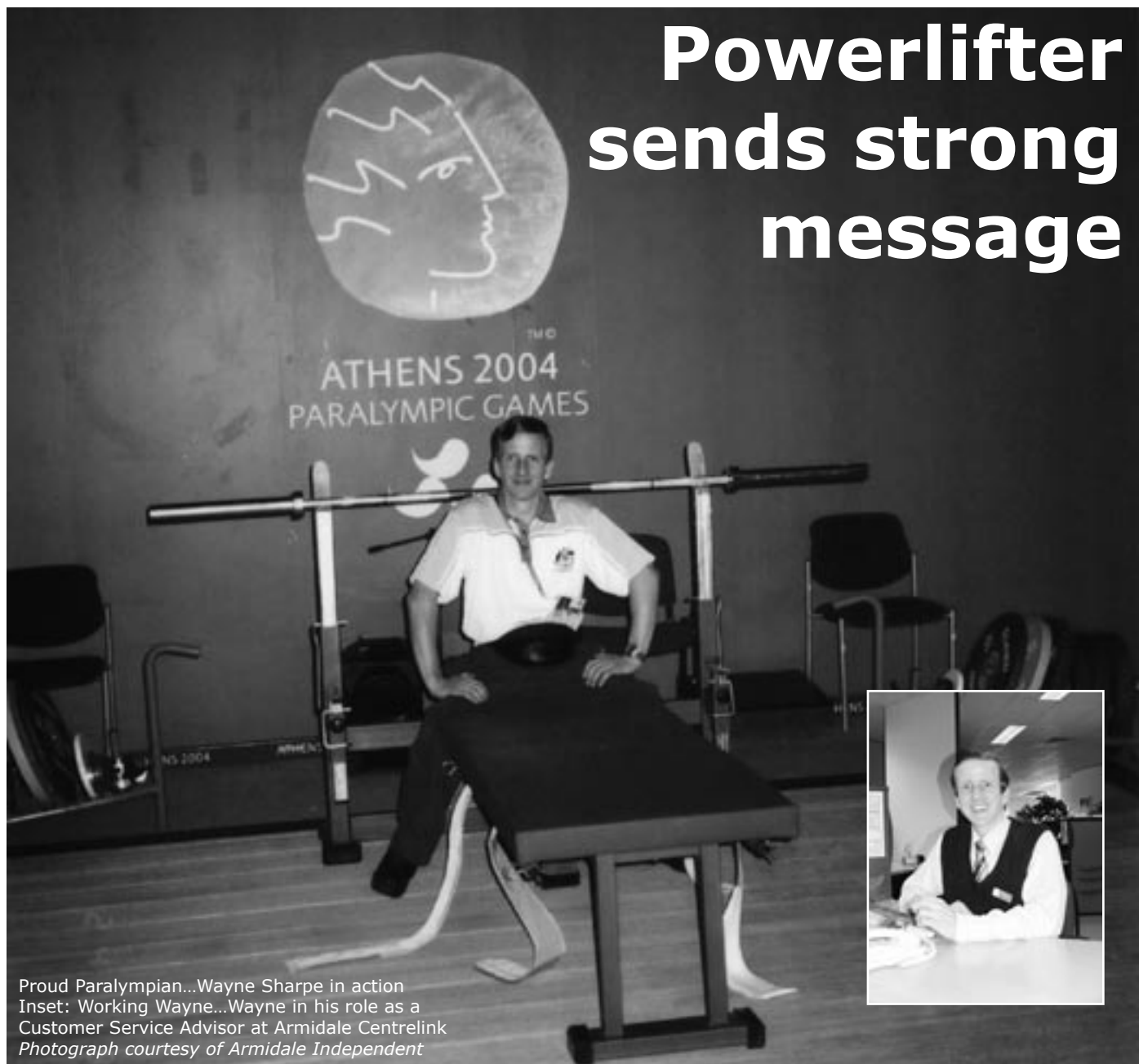
Beach to celebrate the week. The story of Paralympian Wayne Sharpe was profiled in the Tamworth region and an article on his achievements appeared in the *Armidale Independent*, where he asked others to focus on a person's ability, not their disability (see page 15).

The Spina Bifida clinics of both The Children's Hospital at Westmead and the Sydney Children's Hospital were visited by Spinasauros, the official mascot of the Northcott Spina Bifida Group. Spinasauros also paid a visit to The John Hunter Hospital, reuniting with children he first met during Spina Bifida Awareness Week nine years ago. At that time, a photo was published by the *Newcastle Herald*. This year, the children who are now teenagers, cuddled up to Spinasauros one more time, recreating history for the same paper.

Spinasauros made a couple of special appearances, visiting Northcott's Early Childhood Support Service playgroup and schools across NSW, with each visit resulting in media coverage. Students from Jasper Road Public School in Sydney, Hunter Orthopaedic School and Northlakes Public School on the Central Coast gave Spinasauros a rousing reception. Boambee Primary School in Coffs Harbour celebrated the week by organising a colouring competition and mufti day, with \$274 raised for the Northcott Spina Bifida Group.

Unfortunately Spinasauros couldn't get to visit everybody, but we will chase you in 2007!

Powerlifter sends strong message



Proud Paralympian...Wayne Sharpe in action
Inset: Working Wayne...Wayne in his role as a
Customer Service Advisor at Armidale Centrelink
Photograph courtesy of Armidale Independent

PARALYMPIAN and Commonwealth Games Representative Wayne Sharpe of Armidale is used to lifting heavy weights, so the 36-year-old was more than qualified to send one strong message for Spina Bifida Awareness Week 2006: "Look at the person first before you look at their disability".

Wayne, who is supported by Northcott Disability Services in Tamworth, has spina bifida. Known to his mates as 'Sharpie', he has not let his disability restrict his view on life.

Having represented Australia in Benchpress powerlifting since 1989, the powerlifter has competed in the 2002 Commonwealth Games in Manchester, England and both the Sydney 2000 and Athens 2004 Paralympic Games. Wayne also holds the Australian record for powerlifting in the 48kg and 52kg disability divisions, yet despite his impressive record of powerlifting achievements, Wayne maintains that being able to contribute to his community is something he takes the most pride in.

Working full-time at Armidale Centrelink as a Customer

Service Advisor for the past 17 years, Wayne finds his workplace inclusive and enjoys his job.

"My job is both challenging and rewarding, as I have the opportunity to meet and talk to a variety of different people," Wayne said. "My employer sees me like any other staff member, and I think that's the right thought process to have".

Aiming to compete in the 2008 Beijing Olympic Games, Wayne will spend the next two years leading up to the Games training at the gym four days a week, in addition to attending regular competitions and camps. The inspiring Paralympian wouldn't have it any other way.

"I enjoy training and it's important to enjoy it," Wayne said. "If I'm not 100 percent committed to something, I don't see a reason for me to pursue it".

As an active member of his community, Wayne hopes to encourage other people with a disability to achieve their own goals and asks everyone to focus on a person's ability, not their disability: "Don't let your disability, or anyone for that matter, hold you back from what you want to achieve," Wayne said.

“The Rollercoasters” prove there’s ability in disability

THREE women with spina bifida took on the challenge of raising the awareness of spina bifida in particular and disability in general. Kelly Traynor, 25, Tabatha Lloyd, 28 and Karen Downton, 28 formed a team called “The Rollercoasters” and competed in the 2006 Sun Herald City2Surf.

The women, who all use wheelchairs for mobility, tackled the event with determination and grit, raising funds for Northcott Disability Services at the same time.

Karen, who has spina bifida, participated in the 14km race for the second consecutive year. Karen’s motivation this year was to help raise awareness of the ability of people with a disability.

“Completing the City2Surf last year was the most inspirational experience I’ve ever had and I really enjoyed participating in it again,” Karen said. “Spina bifida is not a death sentence, there is ability in disability.”

Tabatha read about Karen’s success in the last edition of *Torque* and answered Karen’s call to form a team.

“I was inspired by the article to do something different,” Tabatha said.



Kelly Traynor (left) with Tabatha Lloyd on the day.
Inset: Karen Downton.

Kelly was motivated to complete the race in order to change the perception of people with a disability.

“Because you are in a wheelchair, people generally think you can’t do anything for yourself,” Kelly said. “It is not true. I am perfectly capable of living an independent life.”

The “Rollercoasters” presented a \$1715 cheque to Glenn Gardner, CEO of Northcott Disability Services, and Diana McIntosh, event organiser of Koncert 4 Northcott, during a special presentation ceremony that took place at Koncert 4 Northcott.

Goodbye and Thanks!

IT is with much sadness that I report the passing of Barbara Melnyk, Occupational Therapist with the Northcott Adult Outreach Team (pictured). Barbara enthusiastically promoted the achievements of people with a disability and was actively involved in Spina Bifida Awareness Week 2006 through presenting at the Ageing with Spina Bifida Forum and touring the regions with Spinasaurus. Barbara chose to continue working at Northcott through her illness and will be very much missed by her colleagues and clients. Thanks Barb!

By Anita Fisher





Diana McIntosh with Dr Carolyn West



Tiffanie Hill.



Ashton Chipi and Bailey Amos-Minahan from Northcott's Early Childhood Support Service with Spinasaurus.



Robert D'Costa.



The Robertson Brothers



Jarrod Barlow, Christie Ratcliffe, Teegan Pryjma, and Alex Carlton with Spinasaurus at John Hunter Hospital in 1997. Photo courtesy of the Newcastle Herald.



Spinasaurus with students from Jasper Road Public School.

Tiffanie Hill, Spinasaurus, Joanne Traeger and Diana McIntosh.



The same children, who are now teenagers reunite with Spinasaurus at John Hunter Hospital.



Ben Allen, Shaun Morgan, Lorraine Morgan and Geoff Withers Wagga Beach BBQ. Photo courtesy of the Daily Advertiser Wagga.

Spinasaurus spreads the word

SPINASAURUS made various visits to schools across NSW during Spina Bifida Awareness Week 2006. Each visit resulted in members of the Northcott Spina Bifida Group having their stories told in their local media. Here are two of those stories.



Making a new friend...Spinasaurus with Kimberley White at Northlakes Public School

Central Coast, NSW – Kimberley White

Kimberley White is an active girl who enjoys school and making friends. The 10-year-old, who has spina bifida, was delighted to make a new friend when Spinasaurus visited her classroom at Northlakes Public School on the Central Coast.

Kimberley's grandparents and guardians, Jan and Kerry Vine, who use the Central Coast Spina Bifida Parent Support Group, attended the school for the special visit.

Kimberley, who uses artificial foot orthoses (AFOs) to assist with her mobility and a shunt to drain the excess fluid from her brain, actively participates in a variety of school sports and is involved with the Girl Guides Association.

"Every time Kimberley comes out of hospital after being sick, she wants to head to school straight afterwards," Jan said. "Doctors said Kimberley would never walk or talk and she's proved them all wrong, as she runs, rides a bike and likes to play practical jokes, just like any of her other classmates."

Philip Hudson, Founder and Coordinator of the Central Coast Spina Bifida Support Group, spoke to Kimberley's class about his achievements living with spina bifida, including completing the Olympic Torch relay.

"It's important to get through to children that people with spina bifida are the same as everyone else," Philip said.

Coffs Harbour, NSW – Emily Silvia

Emily Silvia loves animals, performing and swimming. The five-year-old, who has spina bifida and attends Boambee Public School in Coffs Harbour, was excited to meet Spinasaurus when the big, blue and friendly dinosaur attended her school assembly for a special visit.

The kindergarten student, who uses artificial foot orthoses (AFOs) on both legs to assist with her mobility, enjoyed the Spinasaurus visit. Her parents, Kylie and Kevin, attended their daughter's school for the special visit and said they were proud of the way Emily has accepted her disability.

"Emily likes to try everything, yet knows her limitations and openly says when she needs help," Kylie said. "I always try to reinforce to her that just because she has a disability, it doesn't mean she can't compete in everyday activities."

Boambee Primary School in Coffs Harbour celebrated Spina Bifida Awareness Week 2006 by organising a colouring competition and holding a mufti day. Money was raised for the Northcott Spina Bifida Group.

Spreading the word...Spinasaurus with Emily Silvia



Ageing with Spina Bifida forum a success!



THE Northcott Spina Bifida Group recently hosted an Ageing with Spina Bifida Forum to coincide with Spina Bifida Awareness Week 2006. Dr Carolyn West from The Children's Hospital at Westmead joined Barbara Melnyk, Occupational Therapist with Northcott and Anita Fisher, Manager, Northcott Spina Bifida Group, to discuss health considerations for people with spina bifida as they age. Over 35 people, including individuals and families from across NSW, attended the forum. It was a great opportunity for people to ask questions and also share their experiences. There was a lot of positive feedback on the day.

Some important things that a person with spina bifida who is ageing needs to be aware of:

- Always ask your doctor to check your blood pressure because it is also an indicator for kidney problems.
- Even if you are quite well it is also important to check urine and eyesight every year.
- One of the best ways to detect shunt problems is by having your eyesight checked by an optometrist.
- Don't ignore headaches or neck aches. Frequent headaches and sickness could also be symptoms of shunt problems.
- The effects of ageing for people with spina bifida may include weight gain, more pressure sores, blood pressure problems and reduced mobility.
- If you use a wheelchair for mobility, you use far less energy than someone who is mobile. It is important to maintain a healthy diet.
- Inactivity can lead to osteoporosis (brittle bones), so it's important to include foods rich in calcium and vitamin D in your diet. Skimmed milk and low-fat yoghurt are good sources of calcium, while exposure to sunlight provides us with an active form of vitamin D.
- Some people with spina bifida struggle with depression, which may get worse as they get older because they fear what the future holds. It is important to lead as active a life as possible, and to try to get out and meet people. If you feel depressed it is important to get the support you need, which may mean talking to a counsellor or psychologist.
- People with spina bifida have careers, get married and have children just like people who don't have spina bifida. Ageing can be difficult for everyone, not just people with spina bifida. But taking care of your health, and making sure you seek support when you need it, will help you to live a full and active life.

For more information, contact the Northcott Spina Bifida Group on (02) 9890 0990 or check out the following website: www.asbah.org and click on the link "Spina Bifida" and then click on the link "Living with Spina Bifida."

Are you a parent with a disability?

Are you interested in attending a forum with other parents who have a disability?

The Northcott Spina Bifida Group would like to run a forum for parents with a disability early next year. Perhaps you have a disability and are considering getting pregnant. If so, you may also want to attend.

To express your interest, please contact the Northcott Spina Bifida Group on (02) 9890 0990.